Family Carers Ireland Research Conference 3rd December 2025

#PartnershipInPractice
#familycarers

Family Carers Ireland
No one should have to care alone

Housekeeping

- Bathroom Location
- Exit Location
- Phones on Silent
- Social Media Tags: #PartnershipInPractice

Family Carers Ireland
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Opening Comments

Sharon Foley
Family Carers Ireland, CEO

Family Carers Ireland
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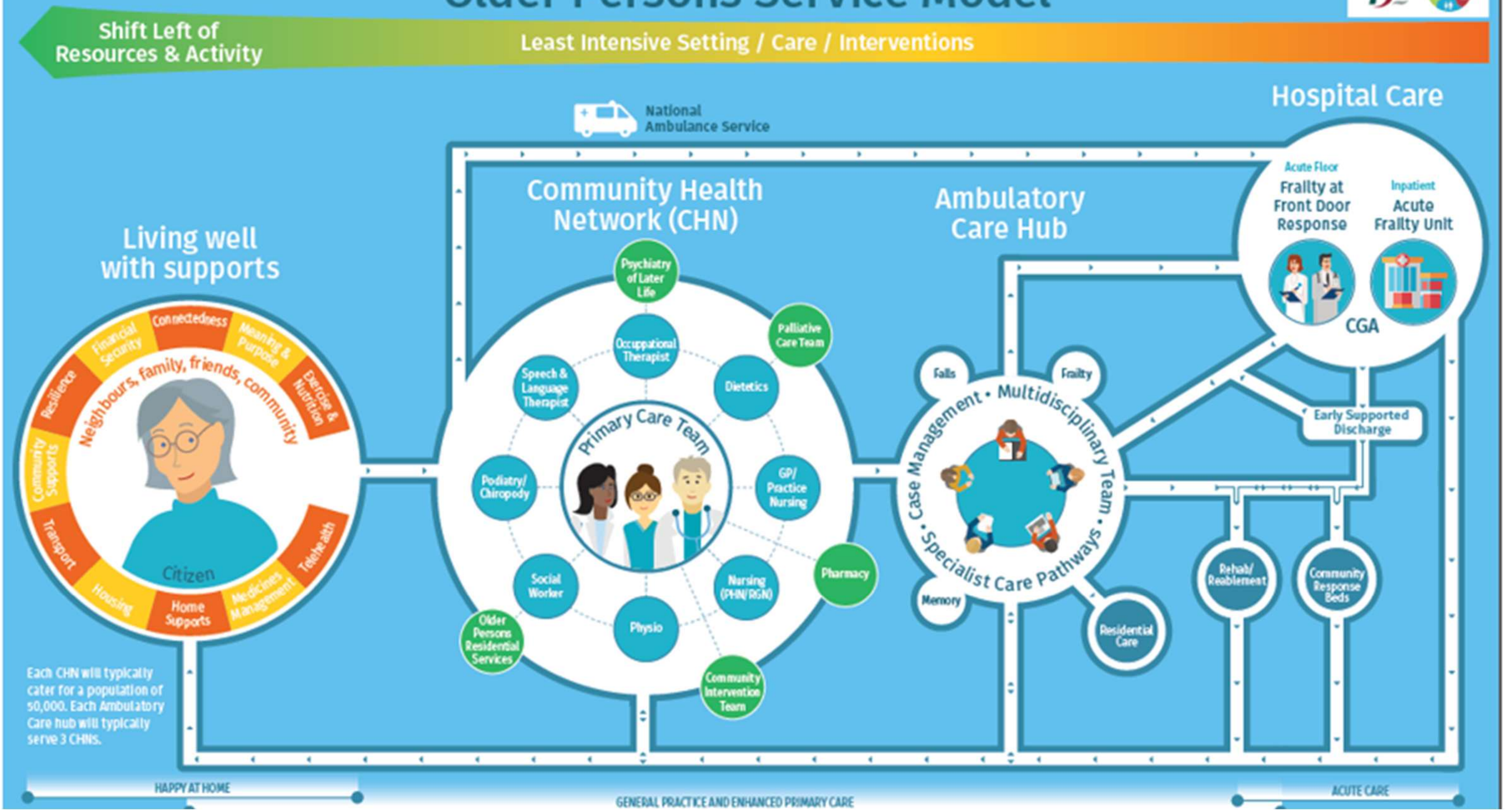
What Does 'Integrated' Mean for Us? Family Carer Inclusion in Interprofessional Collaborative Care Teams Integrating Community-based Care for Older People.

Dr Deirdre O’Donnell, UCD IRIS &

Seoirse O’Mahony (Family Carer and Member of the Eclectic project Public and Patient Advisory Panel)

UCD Centre for Interdisciplinary Research, Education and Innovation in Health Systems (UCD IRIS)
https://www.ucd.ie/nmhs/research/ucdiriscentre/

Older Persons Service Model



Shift Left of Resources & Activity

Least Intensive Setting / Care / Interventions

National Ambulance Service

Living well with supports

Neighbours, family, friends, community

Connectedness
Meaning & Purpose
Exercise & Nutrition
Telehealth
Medicines Management
Home Supports
Housing
Transport
Community Supports
Resilience
Financial Security

Citizen

Each CHN will typically cater for a population of 50,000. Each Ambulatory Care hub will typically serve 3 CHNs.

Community Health Network (CHN)

Primary Care Team

Psychiatry of Later Life
Palliative Care Team
Occupational Therapist
Dietetics
Speech & Language Therapist
GP/ Practice Nursing
Podiatry/ Chiropody
Pharmacy
Social Worker
Nursing (PHN/RGN)
Physio
Older Persons Residential Services
Community Intervention Team

Ambulatory Care Hub

Case Management • Multidisciplinary Team • Specialist Care Pathways

Falls
Frailty
Memory
Residential Care
Rehab/ Reablement
Community Response Beds
Early Supported Discharge

Hospital Care

Acute Floor
Frailty at Front Door Response

Inpatient
Acute Frailty Unit

CGA

HAPPY AT HOME

GENERAL PRACTICE AND ENHANCED PRIMARY CARE

ACUTE CARE

ECC - Community specialist teams for older people

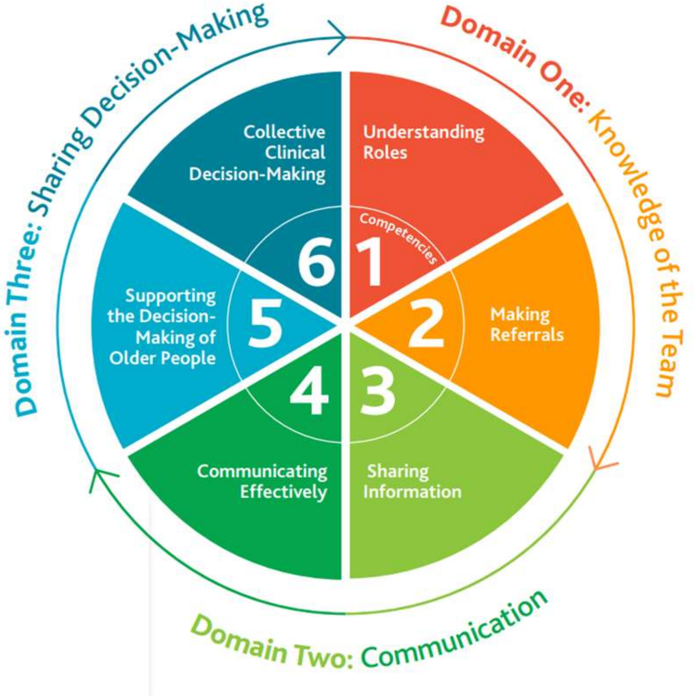
- The ICPOP-CST provide services for older people who:
  - ✓ have complex needs
  - ✓ need specialist multidisciplinary intervention to help maintain their independence and live well at home
- A CGA, where members of the team work together to assess and respond to an older person's needs.
- Includes nurses, a PT, an OT, a SLT, a SW and dietician, under the governance of a consultant geriatrician.
- The team provides access to community-based treatment for eligible older people for a period of up to 6 weeks.
- An older person can get a referral from their GP or consultant geriatrician.

Source: https://www.hse.ie/eng/services/list/2/primarycare/enhanced-community-care/

Research Question

How do community specialist teams working with older people in Ireland develop their knowledge and skills for interprofessional collaboration?

What works? What doesn’t work? For whom does it work and why?



Competencies

Domain One: Knowledge of the Team

1 Understanding Roles

2 Making Referrals

Domain Two: Communication

3 Sharing Information

4 Communicating Effectively

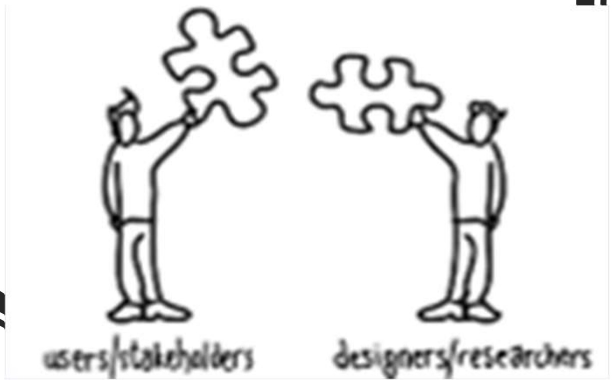
Domain Three: Sharing Decision-Making

5 Supporting the Decision-Making of Older People

6 Collective Clinical Decision-Making

ECLECTIC Team

Public and Patient Advisors:
- Seoirse O’Mahony
- Anne Drury
- Mary McCarthy
- Lilian Finucane
- Thelma Doran



UCD Health Systems

- Dr Deirdre O’Donnell (Principal Investigator)
- Marie O’Shea (Project Manager)
- Dr Sahar Hammoud (Post Doctoral Fellow)
- Chloe Green (Research Assistant)
- Dr Éidín Ni Shé
- Dr Carmel Davies
- Dr Sarah Donnelly
- Dr Gráinne O’Donoghue
- Dr Aoife De Brún

National Clinical Programme for Older People (NCPOP:
- Prof Graham Hughes (NCPOP Clinical Lead)
- Helen Whitty (NCPOP Programme Manager)
- Catherine Devaney (NCPOP Health and Social Care Professional Clinical Lead)
- Deirdre Lang (NCPOP Nursing lead)

Research Design Overview

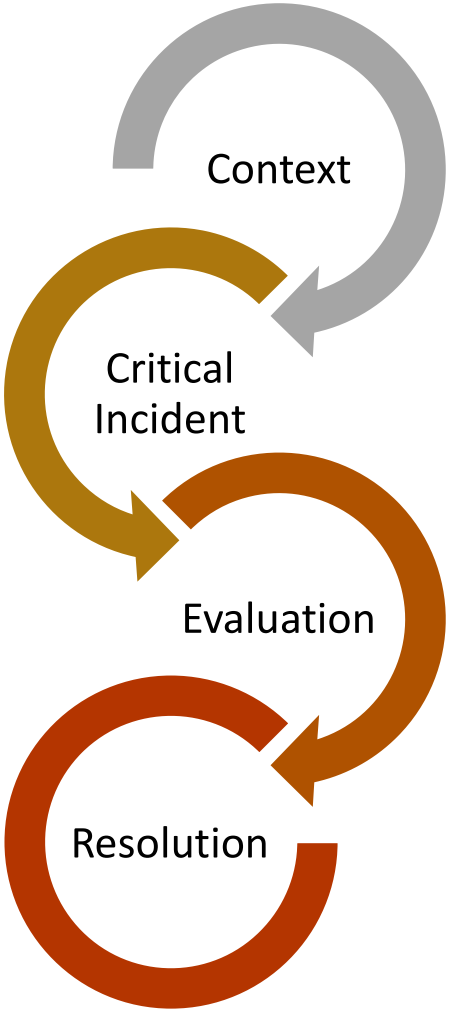
- **Work Package One**
  - ➢ Realist review and synthesis of evidence
    - ✓ Published peer-reviewed literature
    - ✓ Policy documents, reports, guidance
    - ✓ Stakeholder perspectives
- **Work Package Two**
  - ➢ Case study data collection at three-time points
    - ✓ Four community specialist teams for older people
    - ✓ Observations, interviews, document reviews, surveys
    - ✓ Semi-structured interviews with older people and family carers
- **Work Package Three**
  - ➢ Synthesis of case studies
  - ➢ Curriculum development

Role of Public and Patient Advisors

- Supported research proposal development and identifying the research question
- Advised at each phase of the study (advising on work package design, approach and interpretation of findings)
- Co-designed data collection materials for interviews with family carers and older people
- Co-created the older person and family carer narratives (generated from qualitative interview transcripts)

Storytelling

- Narrative interviews with older people and family carers (N=10)
- Narrative analysis
  - Public and Patient Advisors identified key themes from anonymised interview transcripts (critical incidents)
  - Co-designed stories for each of the themes from a synthesis of the interviews



Context

Critical Incident

Evaluation

Resolution

Serena is the primary carer for her mum, who needs daily support to stay at home.

- Mum is 82 and has had several recent falls, and her memory is deteriorating. I called the public health nurse, who had been visiting Mum regularly, to get some advice. She referred us to a specialist team for older people's care. Mum had a long assessment with the ICPOP team, and we told them our main concern was her memory and getting more help at home. The nurse from the ICPOP team told mum to call the public health nurse to arrange for a referral for home support hours and a memory assessment, as they didn't handle these things. I spent days on the phone, trying to sort it out. Everyone thought someone else was in charge of the basics. We finally got linked with the memory assessment team, and someone put in an application for home support. I don’t know who did it, and I don’t know where it is now. I feel like we are going around in circles. The ICPOP team knew what they did, but everyone else thought they could do the other stuff. It shouldn't be this hard. Families shouldn't have to deal with such a confusing system.

Jim is providing care to his wife, Mary, who has significant mental health challenges associated with dementia

- Mary has been deteriorating rapidly, and since our old age psychiatrist retired, there's no one overseeing her care or medication. Mary is so agitated at night, so I don't get much sleep. I try my best, but I'm barely managing with only one hour of home care a week. Recently, I started experiencing dizzy spells. The GP told me there was nothing physically wrong, but that I was suffering from severe stress. The GP decided to refer Mary to ICPOP, and when they assessed her, I was relieved they agreed to manage her medication as a short-term emergency measure. They asked about my needs; I just broke down. I told them I was barely managing and that I was exhausted. They gave me a number for Family Carers Ireland, telling me to call "when I have the time". I haven't called them. I'm too exhausted. I had hoped for something more, something long-term for both of us. I'm still feeling lightheaded, but I put that down to lack of sleep.

Sinead is a family carer for her mum.

- Last year, my mum started to experience bad back pain, which coincided with a deterioration in her memory. Our GP referred us to the ICPOP team, and they provided a care plan which included physical exercises. Mum's pain was getting worse, and she kept forgetting to take her medications. I received a call from the ICPOP team, and they said there was an appointment available at the clinic that same day. I was working and couldn’t change my plans at such short notice. Thankfully, my brother was able to take Mum. That evening, I went to see Mum, and my brother was there. When I asked about the appointment, he didn’t have any information because he didn’t go in with her. I tried to call the clinic, but the paperwork didn’t provide the name of the person involved with her assessments or care. I was frustrated because Mum had consented for me to be involved in her care. I’m the one who sees her every day, I know her routines, and I can provide the most accurate information, but I can’t make appointments at the last minute. It is hard to juggle everything. I am just trying to do my best for Mum.

Margaret is looking after her husband Pat, who had a stroke and just returned home from the hospital.

- Pat and I have been married for 60 years. He had a stroke and was in hospital for nearly two months. Now he's home, but he's weak on one side and struggles with everyday things like showering. The doctor at the hospital referred us to the ICPOP team to help. The ICPOP team, including a physio and OT, came to our house. They gave Pat exercises and added a shower chair and grab bars. I told them we were only receiving 2 hours of home support a week, when we were approved after assessment for 18 hours. The social worker on the ICPOP team helped us to advocate for the fulfilment of the allocation, but they said there was just not enough home care staff. We're managing for now, but I am always worrying that Pat might fall. I feel awful contacting the ICPOP team all the time to ask questions, but I don’t know who else to call. We were approved for 18 hours of home care, but can't get it. The ICPOP team are specialists who shouldn’t need to fill the gaps left by a struggling home support system. It's not fair to them, and it's not fair to us.

Key mechanisms for meaningful inclusion of family carers into a team-based approach to care integration

- Clear communication
  - Interpersonal communication and information sharing
  - Supporting the decision-making of older persons and family carers
- Access to information about the care plan
  - Two-way information sharing
- Key worker or case coordinator
  - A point of contact for older persons and family carers
- Support with system navigation (e.g. a dashboard)
  - Understanding where to go. How the system works
  - A central repository of information designed for and by carers and older people – a place where we can go to find out what we can expect
- Commitment to resource home care
  - Policy - Regulation
  - Government investment

tilda
Staidéar Fadaimseartha na hÉireann um Dhul in Aois
The Irish Longitudinal Study on Ageing

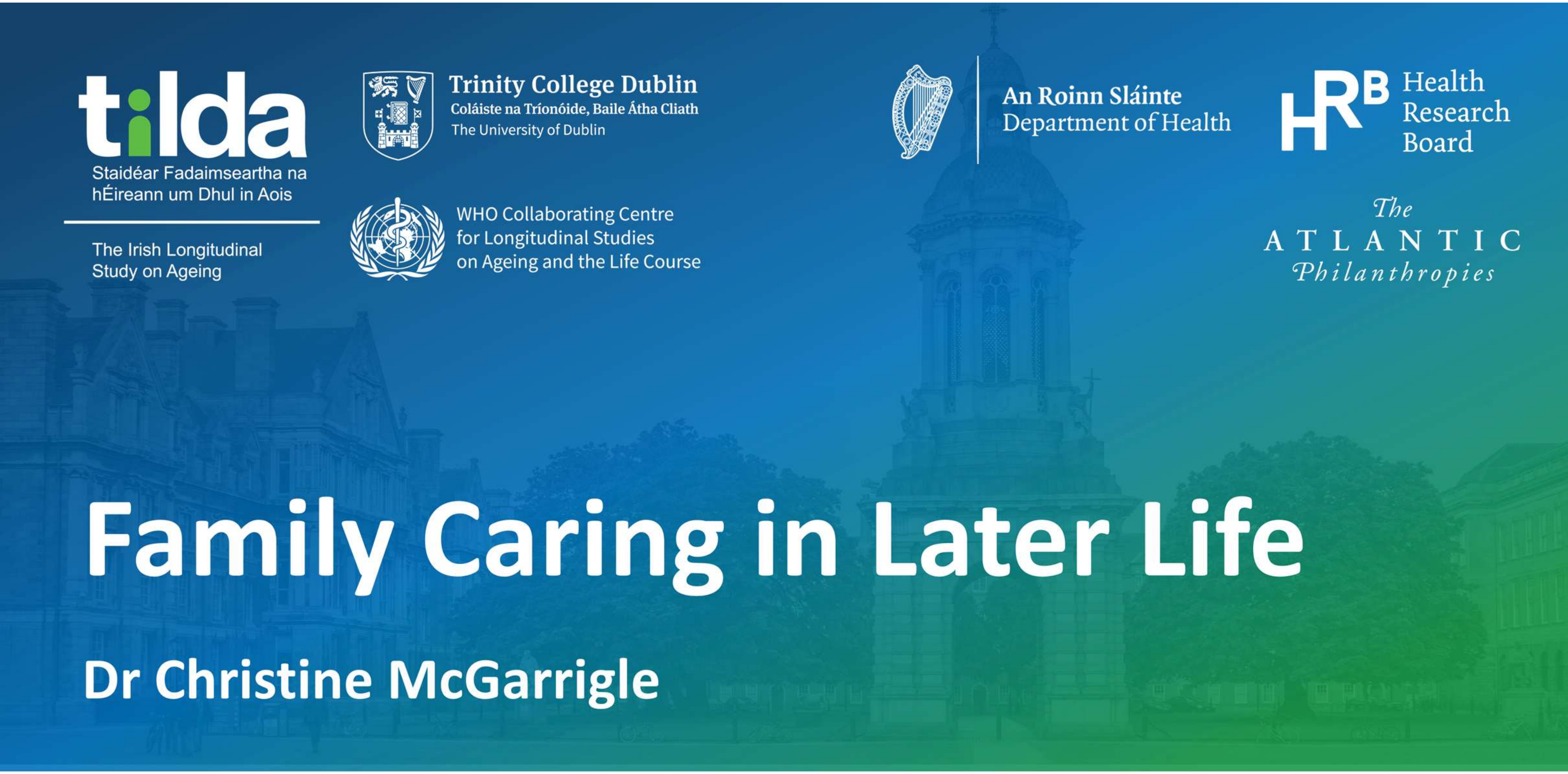
Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

WHO Collaborating Centre
for Longitudinal Studies
on Ageing and the Life Course

An Roinn Sláinte
Department of Health

HRB Health Research Board

The ATLANTIC Philanthropies



Family Caring in Later Life

Dr Christine McGarrigle

C McGarrigle is funded through NIA award RF1AG 088002

Background

Community-based care can facilitate ageing in place and has the potential to delay admission to a nursing home and improve quality of life.

TILDA has highlighted that a substantial proportion of caring for older adults is unpaid, informal care by a family member.

Caring networks are complex and transitions into and out of the caring role in addition to sharing tasks with other more specialised caregivers becomes increasingly important, particularly as the care recipient’s health decreases.

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Staidéar Fadaimseartha na hÉireann um Dhul in Aois
The Irish Longitudinal Study on Ageing

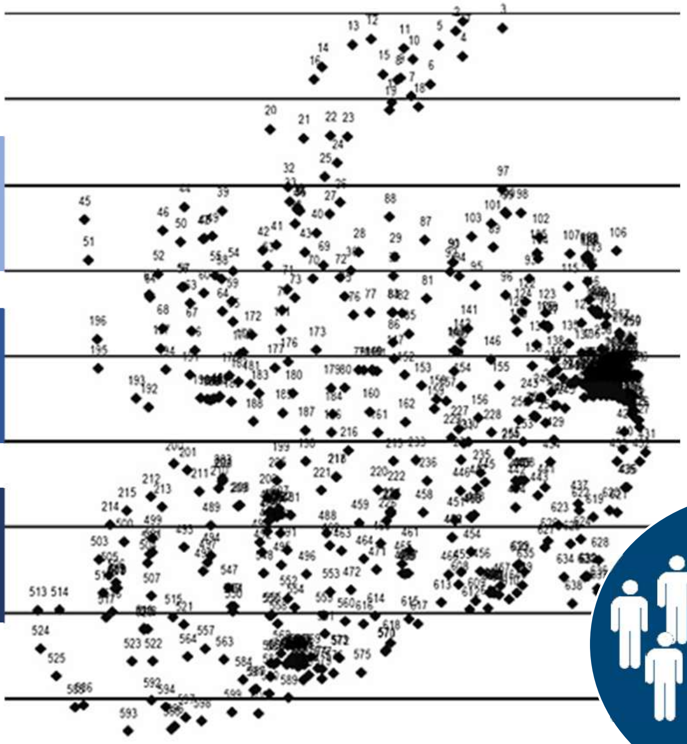
Study Design

- 1 in every 156 aged 50 and over in Ireland
- Random sampling, equal probability of selection
- Every 2 years

Interview

Questionnaire

Health Assessment



8,504

Population receiving care – difficulties with activities

Instrumental Activities of Daily Living (ADLS)

Preparing a hot meal

Doing household chores

Shopping for groceries

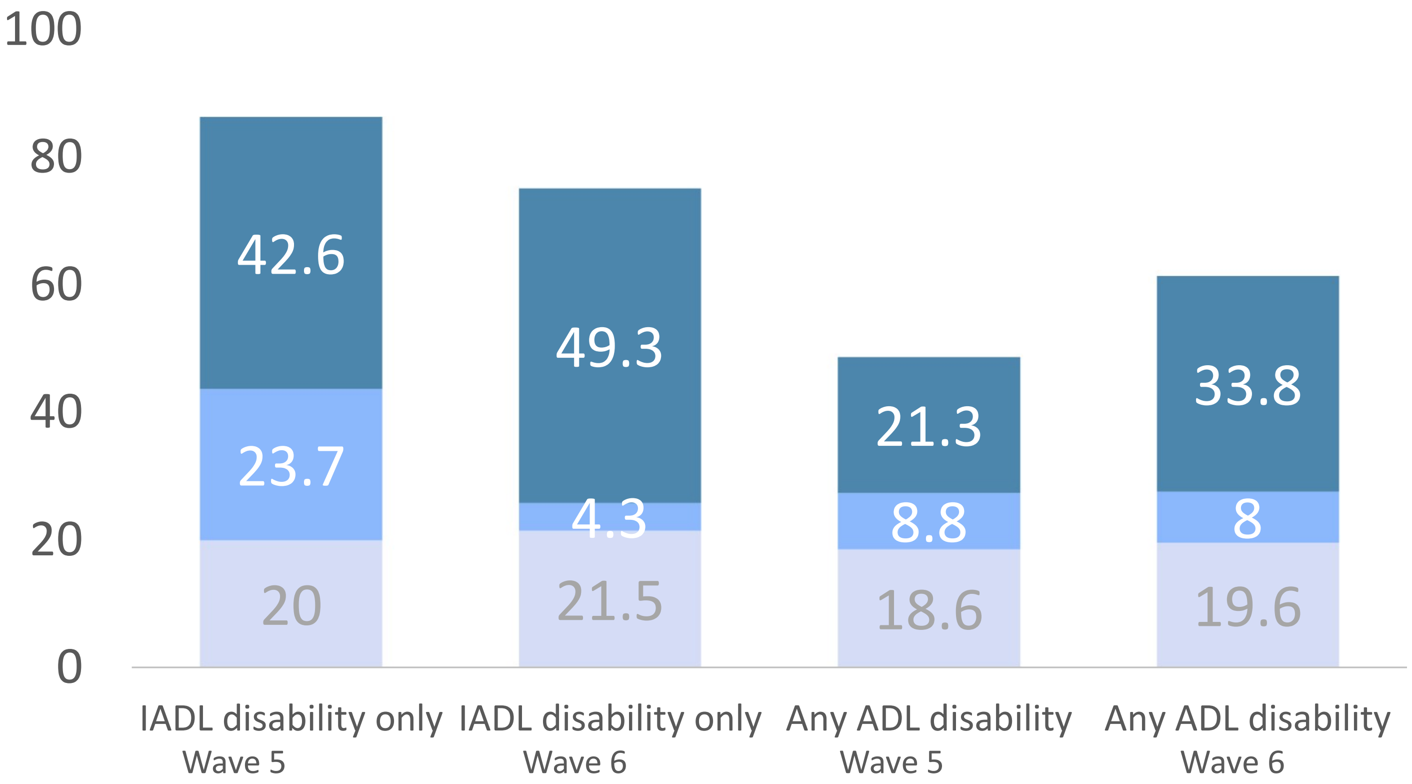
Making telephone calls

Taking medications

Managing money

Activities of Daily Living (ADLS)

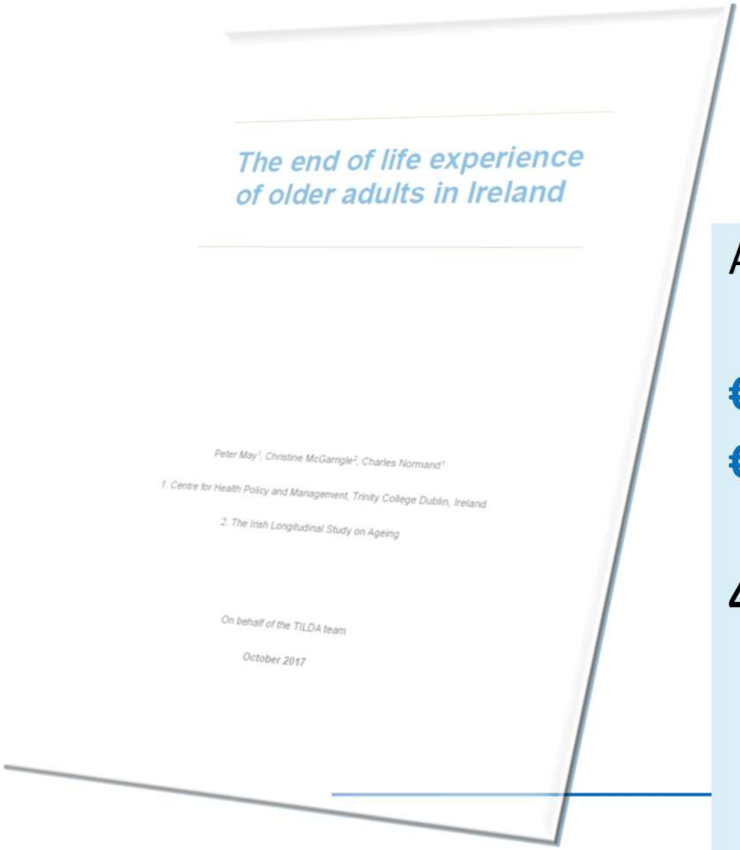
State and private home support and family care



For those with IADL disability 49% of care received is family care - increased to 65% in Wave 6

For those with ADL disability 44% of care received is family care - increased to 55% in Wave 6

End of life and family care



The end of life experience of older adults in Ireland

Peter May[1], Christine McGarrigle[2], Charles Normand[1]

1. Centre for Health Policy and Management, Trinity College Dublin, Ireland

2. The Irish Longitudinal Study on Ageing

On behalf of the TILDA team

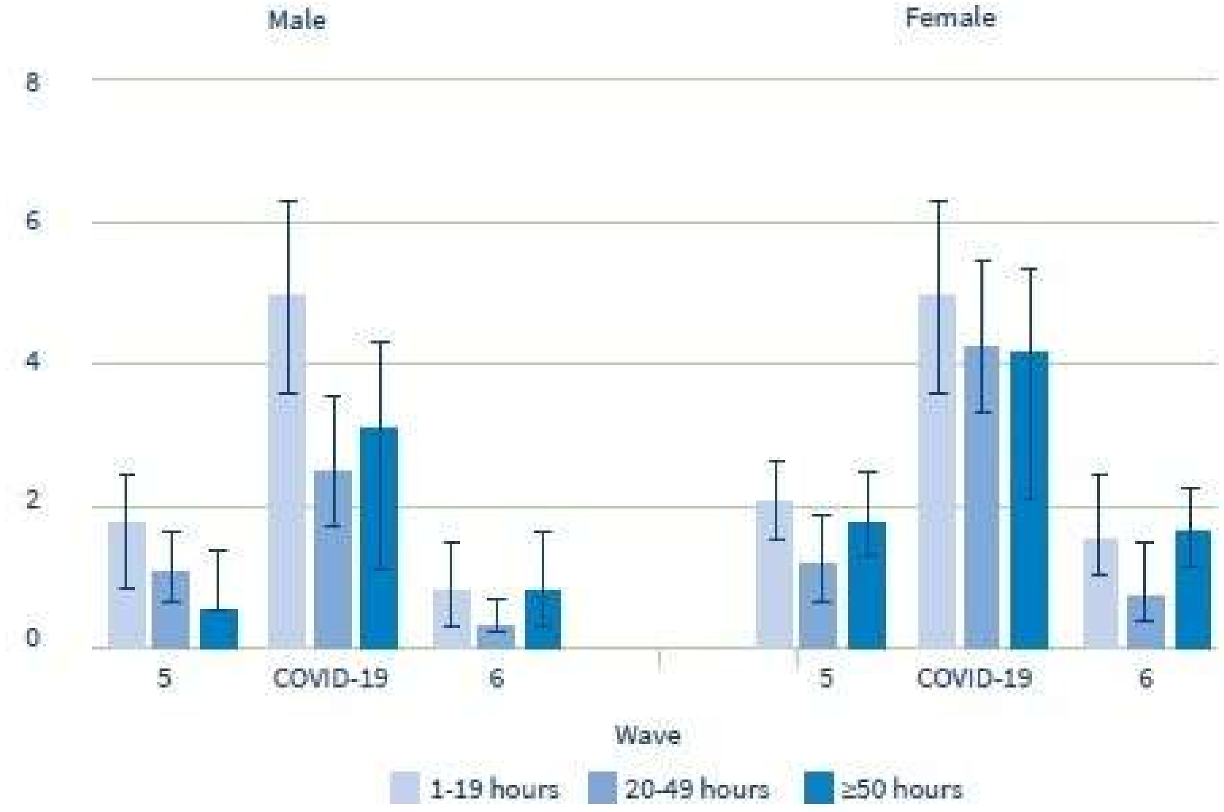
October 2017

An approximate cost of care in last year of life

€ 28,000 formal care costs
€ 20,000 informal care costs

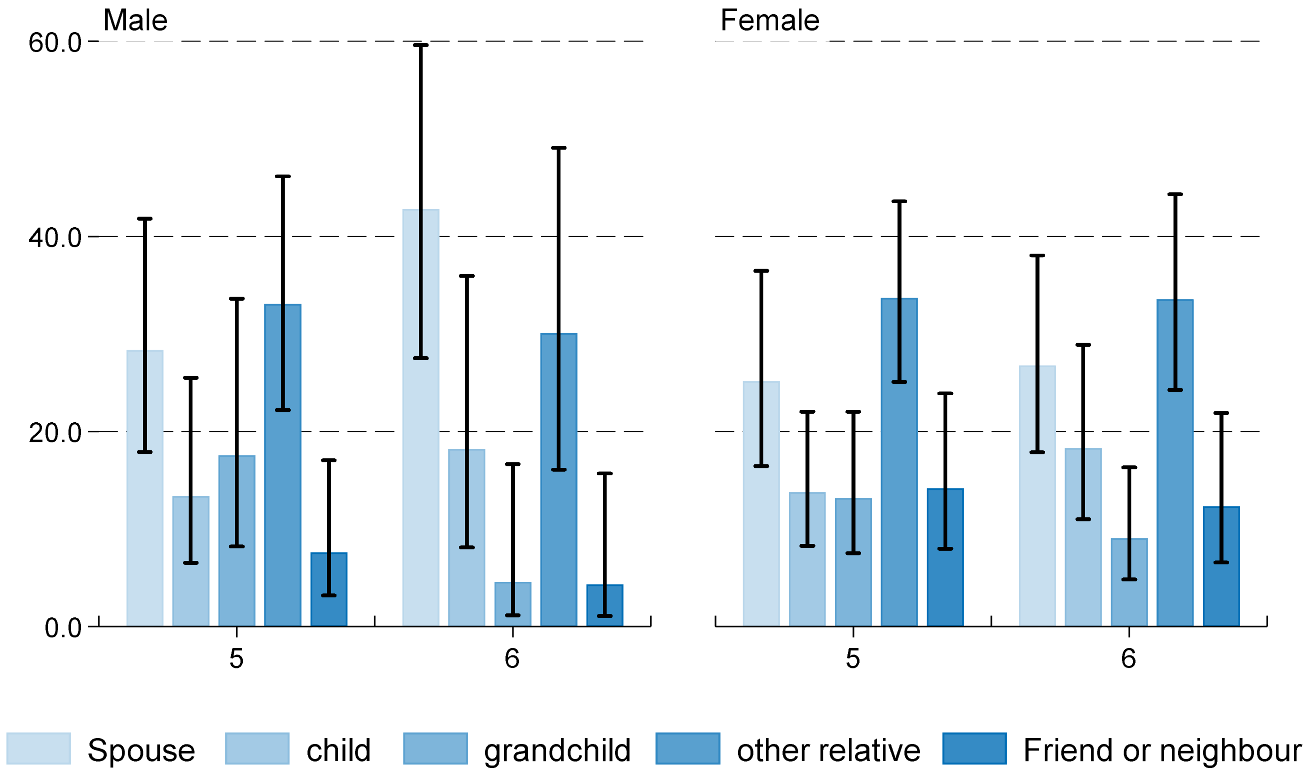
42% of cost of care is provided unpaid by family and friends

Hours of care in the last week



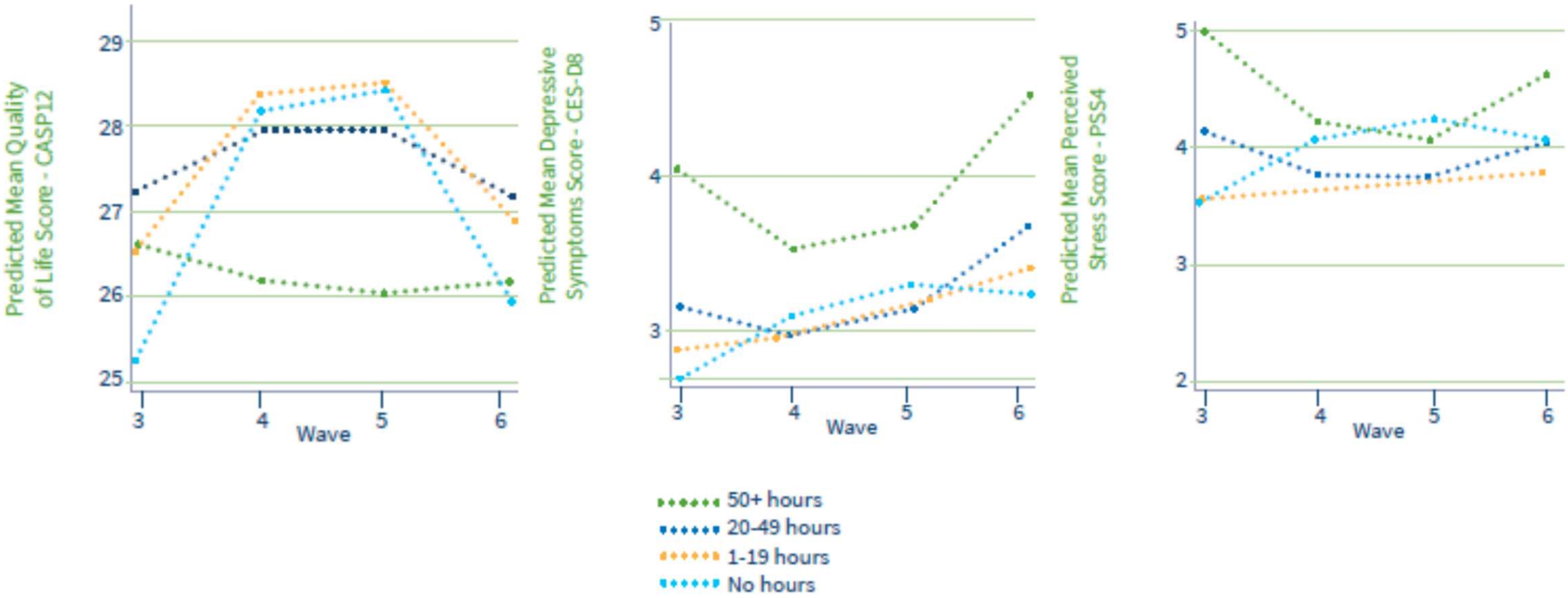
The level of care has returned to pre-pandemic levels in those aged 60 years and older, 3% of men and 5% of women, highlighting a small but consistent gender difference

The main care recipient for those who report they cared for someone in the last month



Mental health and well-being of carers

Quality of life, Depressive symptoms and perceived stress



Caregivers who provide more than fifty hours of care each week report poorer mental health and reduced overall wellbeing, highlighting the emotional strain of high-intensity caregiving

Conclusions

To support and encourage family caring, access to state provided home support is crucial, and it helps carers balance work, leisure and caring responsibilities.

Ensuring such support allows both the carer and care recipient to remain in the home for as long as possible, benefitting individuals, families and the broader healthcare system.

As demand for care grows and formal services remain insufficient, family carers bear more strain, which negatively impacts their health and ultimately, the quality of care.

TILDA is supported by

An Roinn Sláinte
Department of Health

HRB
Health
Research
Board

The
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Irish Life

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

CARDI
Centre for Ageing Research
and Development in Ireland

Taighde Éireann
Research Ireland

Family
Carers
Ireland
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RSA
Údarás Um Shábháilteacht Ar Bhóithre
Road Safety Authority

NIH
National Institutes
of Health

ENTERPRISE
IRELAND
where innovation means business

Clár Éire Ildánach
Creative Ireland
Programme

HORIZON 2020

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Thank You

Acknowledgements:
Thank you to the TILDA participants for their generosity with their time and without whom this research would not be possible

Get in touch with us:

www.tilda.ie

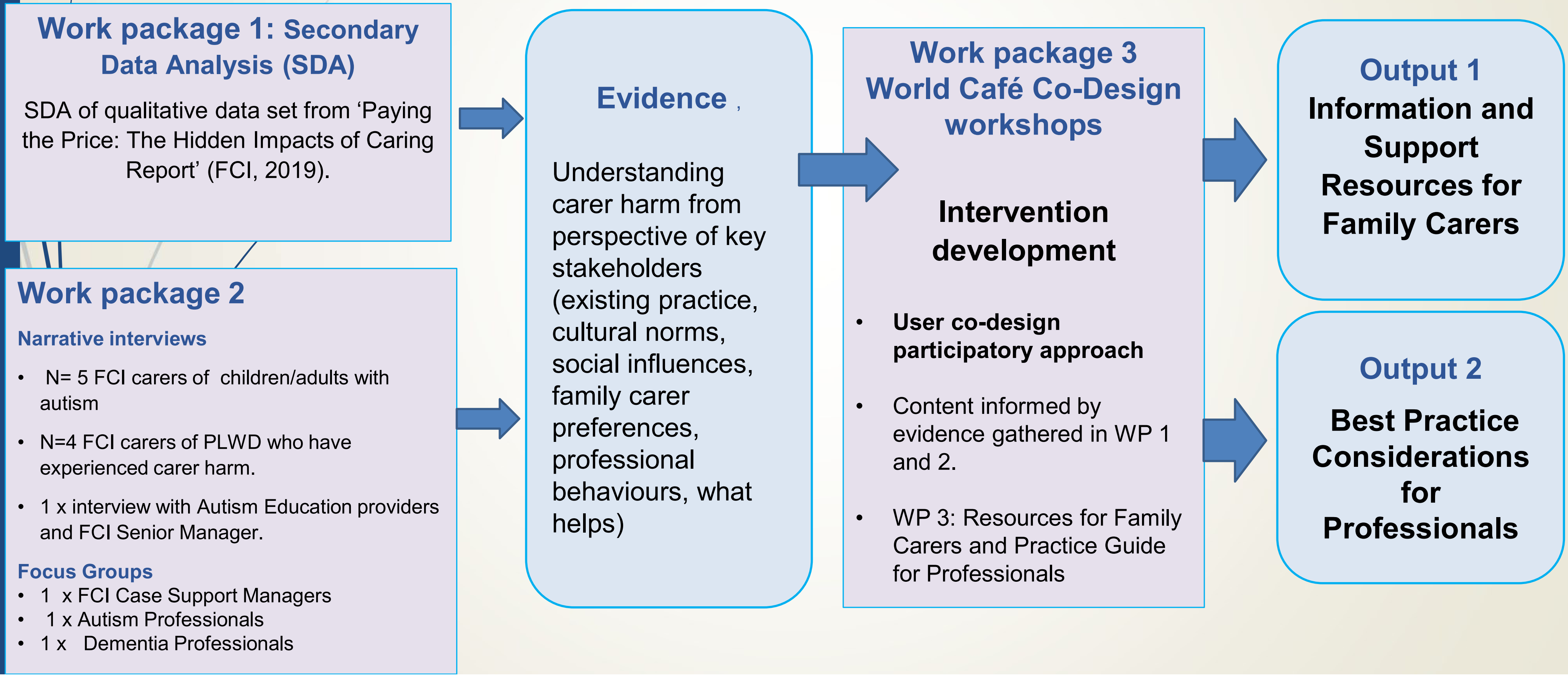
Two years on: Reflecting on the Impact of the Understanding Carer Harm Project on Policy, Practice and the Lived Experience

Dr Sarah Donnelly, Associate Professor of Social Work, UCD &
Sinead Tighe, Family Carer

Research Design

Understanding Carer Harm

Research questions: What are the perceptions and experiences of family carers of carer harm by family carers and how can they be better supported by professionals?



Work package 1: Secondary Data Analysis (SDA)

SDA of qualitative data set from ‘Paying the Price: The Hidden Impacts of Caring Report’ (FCI, 2019).

Work package 2

Narrative interviews

- N= 5 FCI carers of children/adults with autism
- N=4 FCI carers of PLWD who have experienced carer harm.
- 1 x interview with Autism Education providers and FCI Senior Manager.

Focus Groups

- 1 x FCI Case Support Managers
- 1 x Autism Professionals
- 1 x Dementia Professionals

Evidence ,

Understanding carer harm from perspective of key stakeholders (existing practice, cultural norms, social influences, family carer preferences, professional behaviours, what helps)

Work package 3
World Café Co-Design workshops

Intervention development

- **User co-design participatory approach**
- Content informed by evidence gathered in WP 1 and 2.
- WP 3: Resources for Family Carers and Practice Guide for Professionals

Output 1

Information and Support Resources for Family Carers

Output 2

Best Practice Considerations for Professionals

Carer Harm: emerging evidence

- Limited evidence about the nature & prevalence
- **Prevalence:**
  - 44% of carers "regularly experienced" either physical aggression or verbal/emotional abuse from their relative (Family Carers Ireland, College of Psychiatrists and University College Dublin, 2019).
- **Patterns:**
  - Wide range of types of abuse reported: shouting & screaming, damage & destruction of personal possessions/family home, significant levels of physical violence & psychological distress
  - Most victims are women: more parent carers are mothers, intimate care tends to be done by female relatives
  - Carers at risk of harm tend to be embedded in a dyadic intimate relationship &/or a demanding care context: they are also isolated, have few resources & little contact with services (Donnelly & O'Brien, 2022)

The Harmful Role of the ‘Care System’

The role played by welfare policy & services which ‘*can create and aggravate the stresses within (care) relationships and responses to these*’ (Sherwood-Johnson et al. 2023, p5)

- Harm caused or exacerbated due to lack of services and supports and in the way some healthcare professionals engaged with them.
- Professionals spoke about unrealistic and unhelpful societal expectations which were placed on family carers; considered a contributory factor in the harm experienced.
- Expectation that family carers would cope with huge amounts of care alone in situations where professional carers would not be required to.
- Family carers recounted the experience of constantly having to ‘fight’ and ‘beg for help’ in order to stay safe.

Understanding Carer Harm Study Outputs

Family Carers Ireland
No one should have to care alone

Are you experiencing Carer Harm?

If you are a family carer, ask yourself:

Does the person I care for behave in a way that causes me physical injury, emotional pain, or other kind of harm?

In my engagement with professionals and organisations, is my coping capacity and need for support recognized and responded to?

This leaflet may be useful to any family carer experiencing carer harm

Family Carers Ireland
No one should have to care alone

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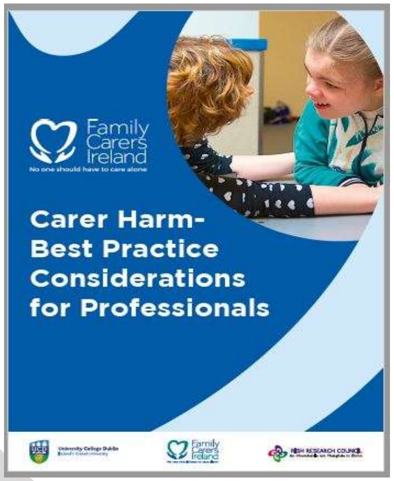
If you are a family carer, ask yourself:

Does the person I care for behave in a way that causes me physical injury, emotional pain, or other kind of harm?

In my engagement with professionals and organisations, is my coping capacity and need for support recognized and responded to?

This leaflet may be useful to carers of people living with dementia



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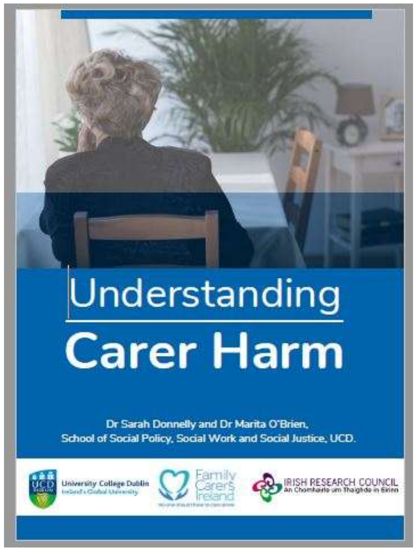
Carer Harm- Best Practice Considerations for Professionals



Understanding Carer Harm

Dr Sarah Donnelly and Dr Marita O'Brien,
School of Social Policy, Social Work and Social Justice, UCD.

University College Dublin
Ireland's Global University

Family Carers Ireland

IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

Family Carers Ireland
No one should have to care alone

Are you experiencing Carer Harm?

If you are a family carer, ask yourself:

Does the person I care for behave in a way that causes me physical injury, emotional pain, or other kind of harm?

In my engagement with professionals and organisations, is my coping capacity and need for support recognized and responded to?

This leaflet may be useful to carers of autistic adults or children

Publications

Carer harm: a challenge for practitioners, services and research

Sarah Donnelly, Louise Isham, Kathryn Mackay, Alisoun Milne, Lorna Montgomery, Fiona Sherwood-Johnson and Sarah Wydall

Abstract

Purpose – *The purpose of this study is to consider how carer harm is understood, surfaced and responded to in contemporary policy, practice and research.*

Design/methodology/approach – *This paper offers a reflective commentary on the current "state of play" relating to carer harm drawing on existing research and related literature. This study focuses on how we define carer harm and what we know about its impact; lessons from, and for, practice and service provision; and (some) considerations for policy development and future research.*

Findings – *The authors highlight the importance of engaging with the gendered dimensions (and inequalities) that lie at the intersection of experience of care and violence and the need to move beyond binary conceptions of power (lessness) in family and intimate relationships over the life course. They suggest that changing how we think and talk about carer harm may support practitioners to better recognise the impact of direct and indirect forms of carer harm on carers without stigmatising or blaming people with care needs. The findings of this study also consider how carer harm is "hidden in plain sight" on two accounts. The issue falls through the gaps between, broadly, domestic abuse and adult and child*

(Information about the authors can be found at the end of this article.)

British Journal of Social Work (2025) **00**, 1–21
https://doi.org/10.1093/bjsw/bcaf004

Exploring unintentional 'carer harm'—Insights from family carers and professionals: An Irish case study

Sarah Donnelly [1,*], Alisoun Milne[2], Marita O'Brien[3], Nikki Dunne[4], and Deirdre O'Donnell[5]

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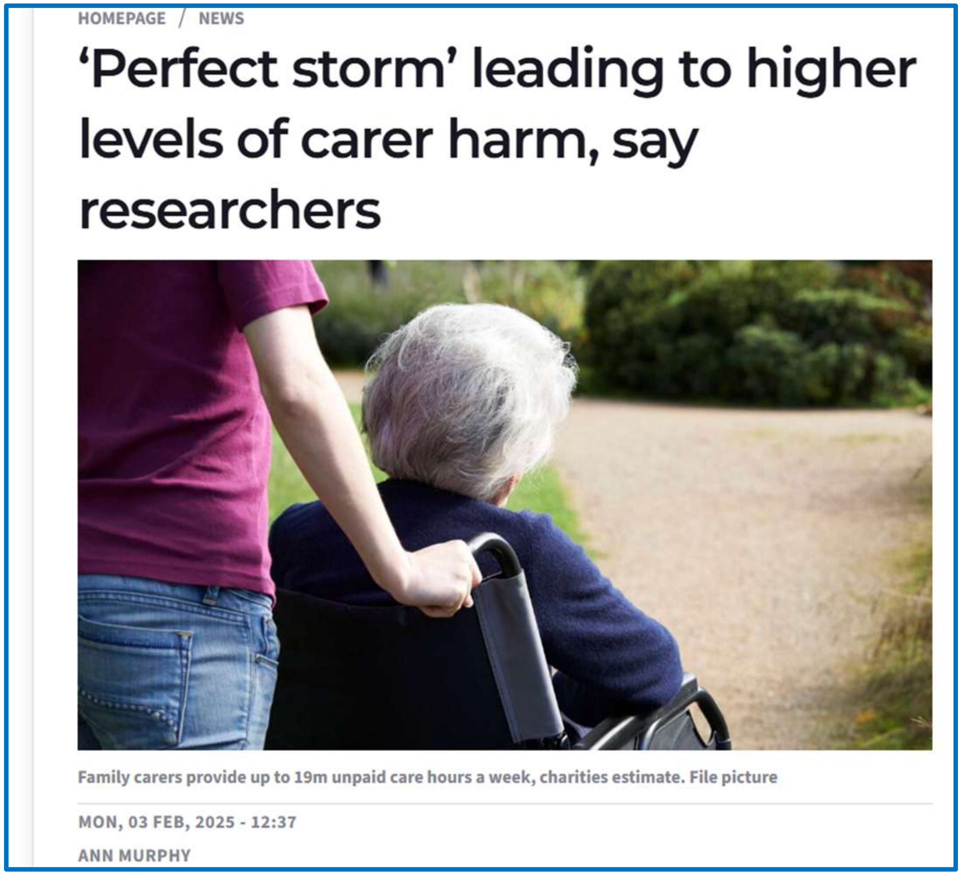
[5] *Assistant Professor of Health Systems, School of Nursing, Midwifery and Health Systems,*

Irish Examiner



HOMEPAGE / NEWS

‘Perfect storm’ leading to higher levels of carer harm, say researchers

Family carers provide up to 19m unpaid care hours a week, charities estimate. File picture

MON, 03 FEB, 2025 - 12:37

ANN MURPHY

HOMEPAGE / NEWS

Little help for family carers suffering 'hidden harm', expert warns

Carers want to protect relatives vulnerable due to dementia, living with disabilities or suffering mental ill-health.

WED, 05 FEB, 2025 - 19:00

NIAMH GRIFFIN

Outreach and Impact

Three awareness-raising webinars

8 National Conference Presentations

10 International Conference/Invited Presentations

Commission on Care for Older People

Willie Bermingham Memorial Lecture, ALONE/IGS

Social Justice Ireland Annual Policy Conference

Welsh Government's Violence Against Women, Domestic Abuse, Sexual Violence Strategy Working Group

Hidden Harm: Utilising the Ethics of Care for Theory Development

- England, Ireland, and Northern Ireland: focus on discourse of duty and familial responsibility.
- Wales and Scotland have moved somewhat toward rights-based, recognition-oriented framings.
- Unpaid care remains largely established as a family responsibility, with the most demanding, unequal, and emotionally complex aspects remaining largely unacknowledged.
- Care relationships are presented implicitly as almost entirely positive, with carers portrayed as virtuous and heroic.
- No ‘choice’ about being a carer
- Interdependency not explicitly recognised

Five Nations Working Group

Assoc. Professor Sarah Donnelly, University College Dublin, Ireland

Dr Louise Isham, University of Birmingham, England

Dr Kathryn Mackay, University of Stirling, Scotland

Emeritus Professor Alisoun Milne, University of Kent, England

Professor Lorna Montgomery, Queens University, Belfast, Northern Ireland

Dr Fiona Sherwood-Johnson, University of Stirling, Scotland

Professor Sarah Wydall, University of Swansea, Wales

THE ETHICS OF CARE

Over to Sinead…

Next Session Begins
At 11:40am

Family Carers Ireland
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Roundtable Discussion:
Communicating Research for Impact

Using Research to Advocate for Change

Clare Duffy
Policy & Public Affairs Manager

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Learning Objectives…

1. **Recognise** that the relationship between research and policy isn’t linear nor always the goal!

2. **Understand** who the players are in the journey to advocate for change.

3. **Consider** some of the characteristics of research that has helped us achieve impact.

4. **Learn** about the key areas to consider when using research to influence policy/practice.

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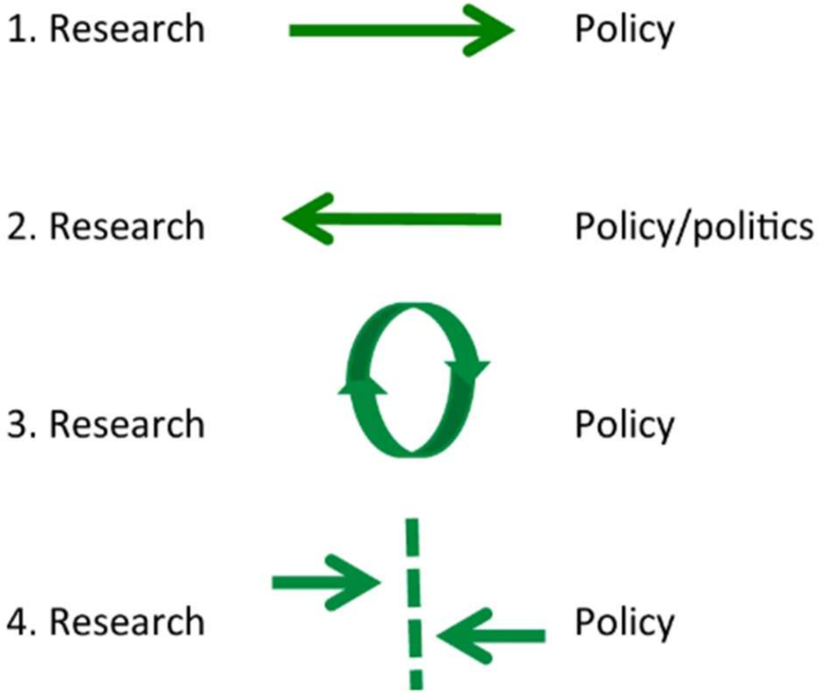
Research – Policy Relations

- Influencing policy shouldn't be the **primary indicator of research impact.**
- Should reward collaborative research that **builds incrementally on a wider body of work and brings subtle conceptual shifts**.
- Focus should be on **rewarding collaboration and knowledge exchange** rather than overly focusing on rewarding policy impacts.



1. Research Policy

2. Research Policy/politics

3. Research Policy

4. Research Policy

Boswell, C., Smith, K. Rethinking policy 'impact': four models of research-policy relations. Palgrave Commun 3, 44 (2017). https://doi.org/10.1057/s41599-017-0042-z

The players…

- Researchers
- PPI – Patients, Carers, CFP
- Funders
- Practitioners/Professionals
- Policy Intermediaries / Advocates
- ‘Policymakers’

The journey between research and policy is complex and dynamic. Players roles will change. However we are all on the same team, striving to make life better for carers.

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Characteristics of research that has helped FCI achieve change

Research that's practical!

Gives 'ammunition for advocacy'

Clear, compelling findings
Concise, impactful and easily communicated

People powered
Driven by the people who live it.

Knows its target audience
Build networks and relationships with policy makers.

Research with purpose
Addresses a real-world problem.

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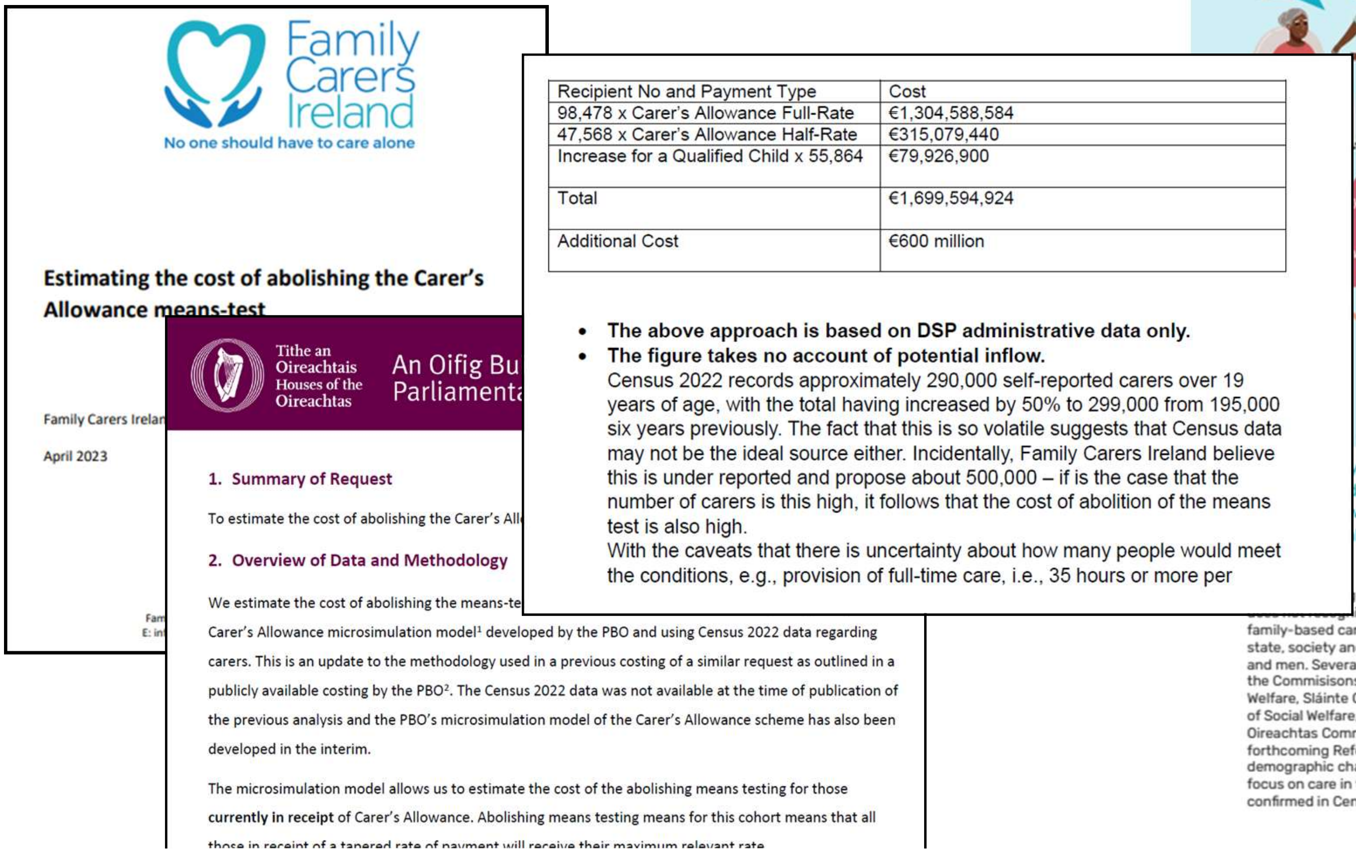
1. Research: Reform Carer’s Allowance

Problem: Conflicting information about the cost of abolishing the means-test.



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Estimating the cost of abolishing the Carer’s Allowance means-test

Family Carers Irelan

April 2023

Fam
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Tithe an Oireachtais
Houses of the Oireachtas

An Oifig Bu
Parliament

1. Summary of Request

To estimate the cost of abolishing the Carer’s All

2. Overview of Data and Methodology

We estimate the cost of abolishing the means-te

Carer’s Allowance microsimulation model[1] developed by the PBO and using Census 2022 data regarding carers. This is an update to the methodology used in a previous costing of a similar request as outlined in a publicly available costing by the PBO[2]. The Census 2022 data was not available at the time of publication of the previous analysis and the PBO’s microsimulation model of the Carer’s Allowance scheme has also been developed in the interim.

The microsimulation model allows us to estimate the cost of the abolishing means testing for those **currently in receipt** of Carer’s Allowance. Abolishing means testing means for this cohort means that all those in receipt of a tapered rate of payment will receive their maximum relevant rate

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Recipient No and Payment Type	Cost
98,478 x Carer’s Allowance Full-Rate	€1,304,588,584
47,568 x Carer’s Allowance Half-Rate	€315,079,440
Increase for a Qualified Child x 55,864	€79,926,900
Total	€1,699,594,924
Additional Cost	€600 million

- **The above approach is based on DSP administrative data only.**
- **The figure takes no account of potential inflow.**
  Census 2022 records approximately 290,000 self-reported carers over 19 years of age, with the total having increased by 50% to 299,000 from 195,000 six years previously. The fact that this is so volatile suggests that Census data may not be the ideal source either. Incidentally, Family Carers Ireland believe this is under reported and propose about 500,000 – if is the case that the number of carers is this high, it follows that the cost of abolition of the means test is also high.
  With the caveats that there is uncertainty about how many people would meet the conditions, e.g., provision of full-time care, i.e., 35 hours or more per

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SUMMARY

Maynooth University
Family Carers Ireland

Towards a Participation Income for Family Carers

y document reflects research by academics in Maynooth University and Family d. Literature reviews, interviews with family carers and a merging of different wledge and experiences led us to propose a new approach to income support lues family care in Ireland.

consensus that Carer’s Allowance ise, value, reward or redistribute family-based care work between the family and the state, society and the market, and between women and men. Several recent policy initiatives including the Commisisons on Pensions and on Tax and Welfare, Sláinte Care, the NESC report on the Future of Social Welfare, the Citizens’ Assembly and related Oireachtas Committee on Gender Equality, and the forthcoming Referendum on Article 41.2 all speak to demographic changes and the need for a greater focus on care in the community and family, as confirmed in Census 2022.

Method

Informing this proposal were feminist literatures on valuing care; international comparisons of how care is valued and innovative income support proposals that all value care and participation. Qualitative interviews with unpaid family carers confirmed the limitations of the means test and inadequacy of Carer’s Allowance to support dignified and appropriate care. Different stakeholders (academics, public servants, NGOs and family carers) examined a proposal for a **Participation Income for Family Carers**. Recommendations and an implementation timeline were developed.

Policy Outcome: Means-test significantly increased

PfG commits '***significantly increase the income disregards for Carer's Allowance in each Budget with a view to phasing out the means test during the lifetime of the Government***'.

€625 2025

€50K Capital Disregard

€1,000

July 2026

€1250 2025

€50k Capital Disregard

(Divide total capital by 2 then multiply by 2 at the end)

€2,000

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2. Research: Young Carers

Problem: Census data on young carers masking the real extent of caring among young people. Young carers under 15 enumerated in Census 2022 was 4,759 - 0.5% of children in that age group.

HSBC 2018 survey showed that 13.3% of young people between the 10-17 years report a caring role. Extrapolation to national population would suggest approx. 67,000 young carers in the age group alone.

Young Carers
IN IRELAND

Insight into the Prevalence and Experiences of Young Carers in Ireland using data from the HBSC 2018 Study.

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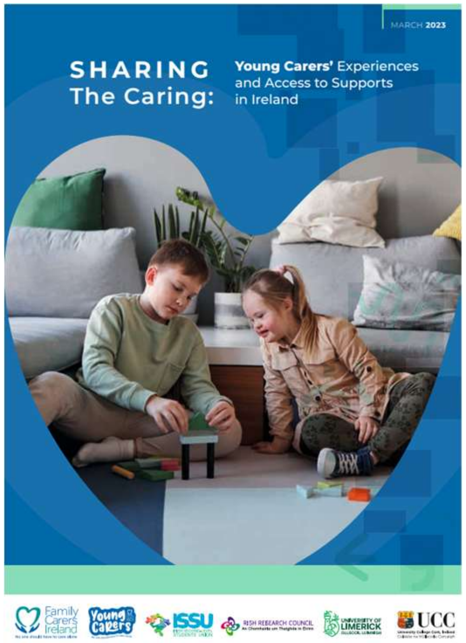
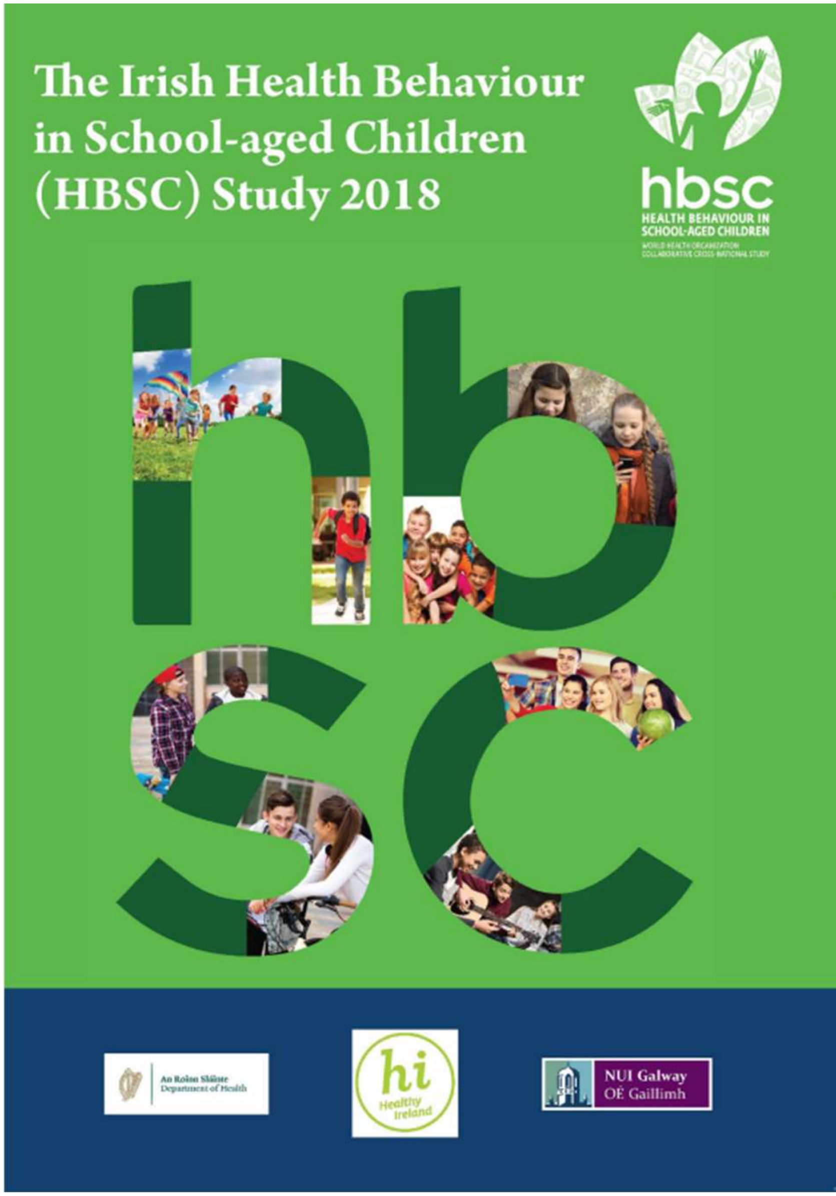


MARCH 2023

SHARING The Caring: Young Carers' Experiences and Access to Supports in Ireland



The Irish Health Behaviour in School-aged Children (HBSC) Study 2018

hbsc
HEALTH BEHAVIOUR IN SCHOOL-AGED CHILDREN
WORLD HEALTH ORGANIZATION COLLABORATIVE CROSS-NATIONAL STUDY

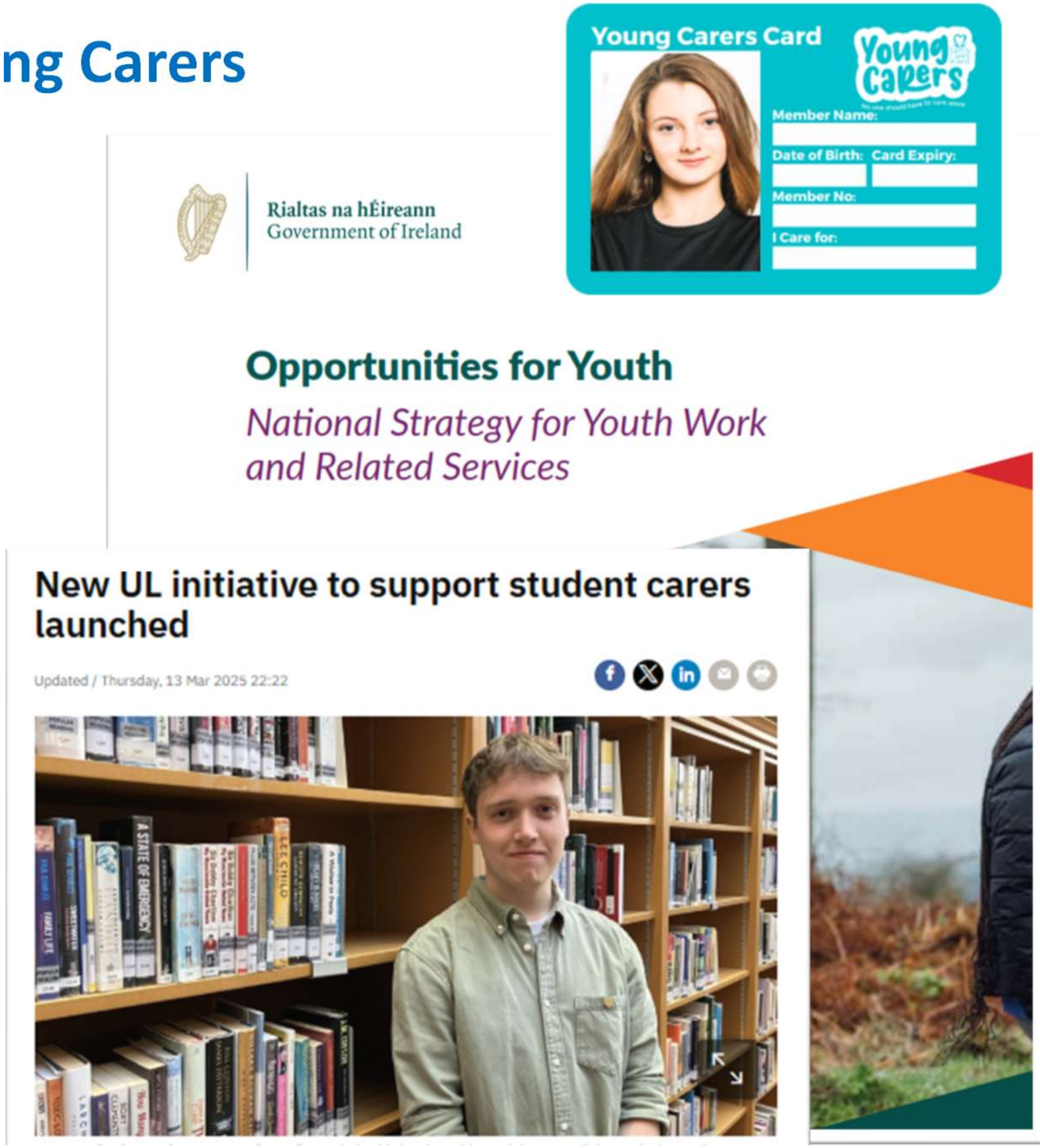
An Roinn Sláinte
Department of Health

hi
Healthy Ireland

NUI Galway
OÉ Gaillimh

Policy Outcomes: Recognition of Young Carers

- Government recognition – responsibility assigned to DCDE.
- National Youth Strategy – two dedicated actions for young carers.
- Young carers named as target group for HEAR access route.
- Introduction of young carer bursary in third level institutions.
- Dormant Accounts funding for young carers.



Young Carers Card

Member Name:

Date of Birth: Card Expiry:

Member No:

I Care for:

Rialtas na hÉireann
Government of Ireland

Opportunities for Youth

National Strategy for Youth Work and Related Services

New UL initiative to support student carers launched

Updated / Thursday, 13 Mar 2025 22:22

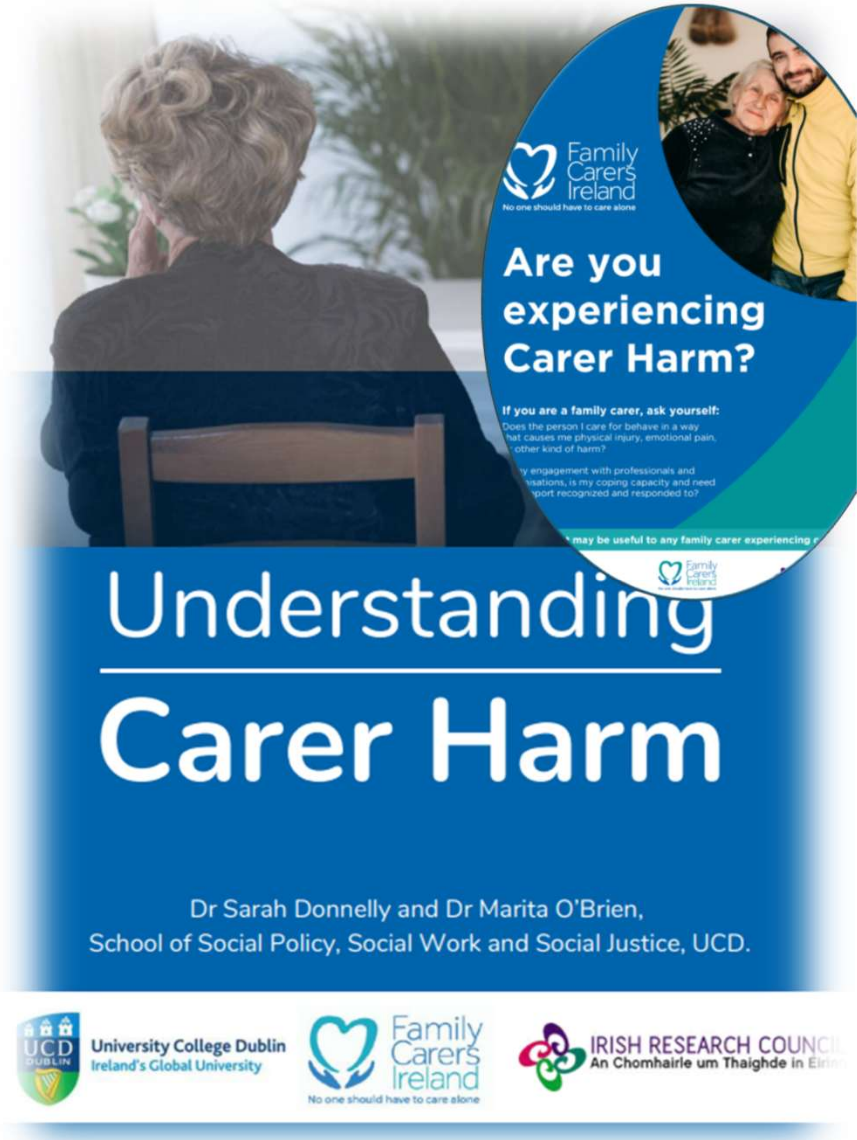
3. Research: Understanding Carer Harm

Problem: Carers' experience of 'harm' was hidden, un-recognised in policy and often misunderstood.

- Research captures an experience of many family carers that was **previously hidden and unnamed**, meaning carers may have felt blame, guilt, or isolation for experiencing this harm.

- Naming 'Carer Harm' allows for **recognition, support, and interventions** tailored to support carers.

- Gives FCI and other advocates a 'mandate' to raise the issue both with carers themselves, health professionals and government.



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Are you experiencing Carer Harm?

If you are a family carer, ask yourself:

Does the person I care for behave in a way
hat causes me physical injury, emotional pain,
other kind of harm?

y engagement with professionals and
isations, is my coping capacity and need
port recognized and responded to?

may be useful to any family carer experiencing

Family Carers Ireland

Understanding

Carer Harm

Dr Sarah Donnelly and Dr Marita O'Brien,
School of Social Policy, Social Work and Social Justice, UCD.

University College Dublin
Ireland's Global University

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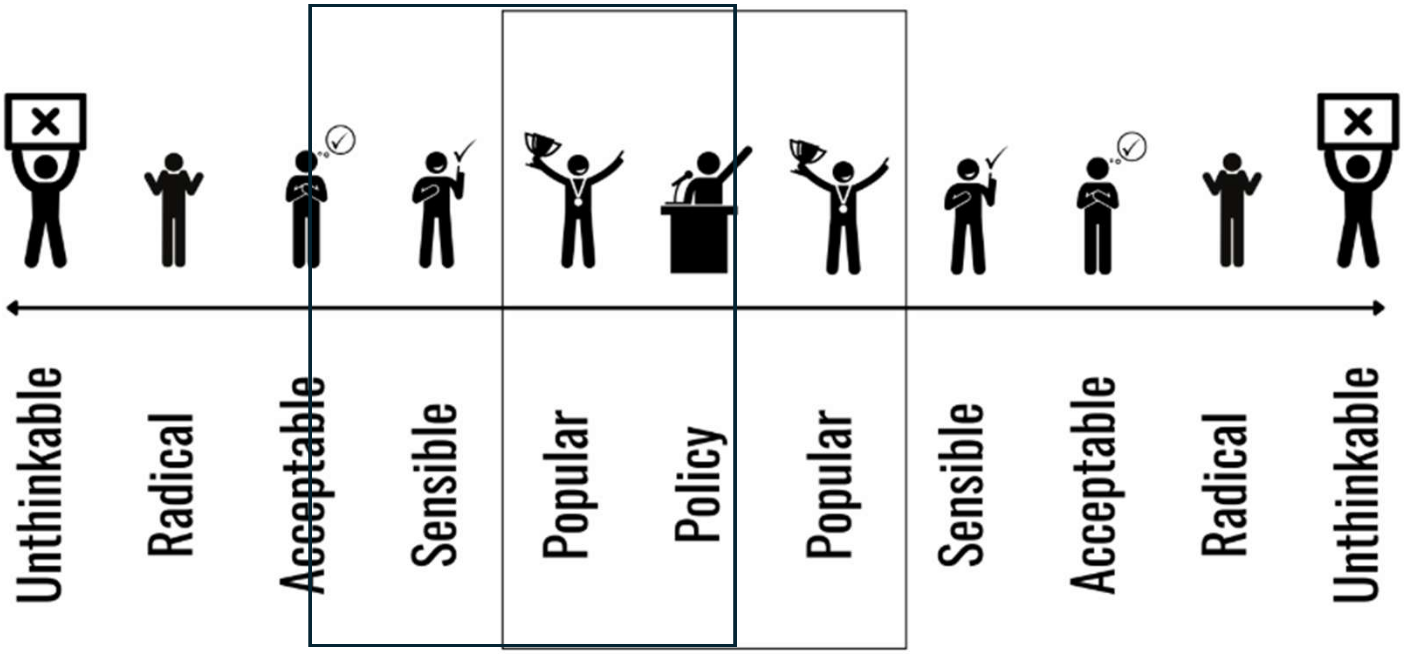
IRISH RESEARCH COUNC
An Chomhairle um Thaighde in É

Policy Outcome: Shifting the Overton Window

Describes the range of ideas considered publicly acceptable at a given time.

Spectrum from **‘unthinkable’ to ‘policy**’.

Shone a light on Carer Harm and began a conversation – **shifting the Overton Window**.



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Few final take aways….

- A change in **policy isn't always the end goal**.
- **Focus on 'policy intermediaries' as well as the 'policymakers':** Identify the actors with the power to change policy, and the actors able to influence policymakers.
- **Open access:** Biggest barrier to evidence-based policymaking is that so much research sits behind pay-walls. Research needs to be available in full, for free and for everyone.
- **Paint a picture:** Simplify complexity, resonate with research audience and motivate them to support a change in policy.
- **Timing:** Research more likely to influence policymakers when presented during a 'windows of opportunity'. E.g. child poverty research in advance of Budget.
- **Areas of Research Interest (ARIs):** List of policy questions/topics an organisation, government dept/agency publish to indicate where they need more research evidence.

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Thank you.

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1800 24 07 24
www.familycarers.ie

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From Research to Impact

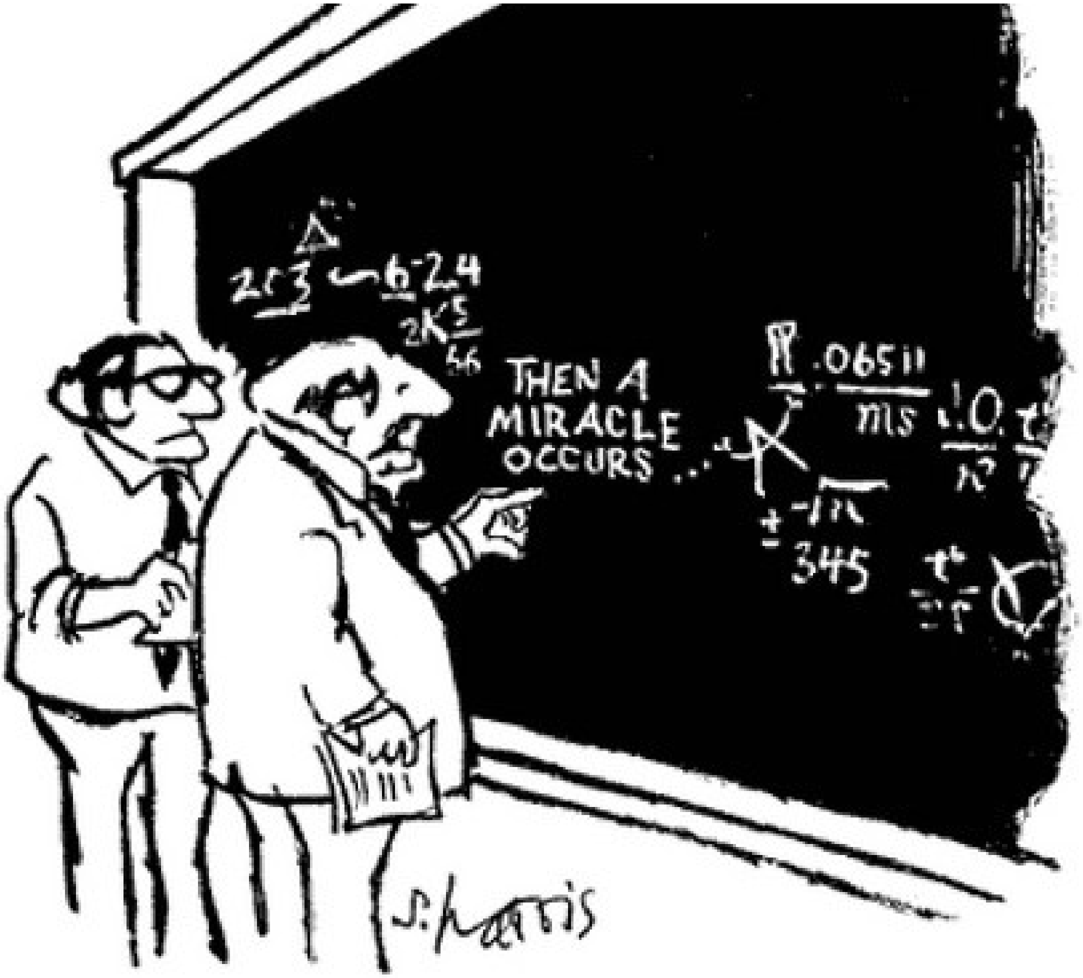
Dr Emma Dorris
Engaged Research Manager, UCD Research

November 2025

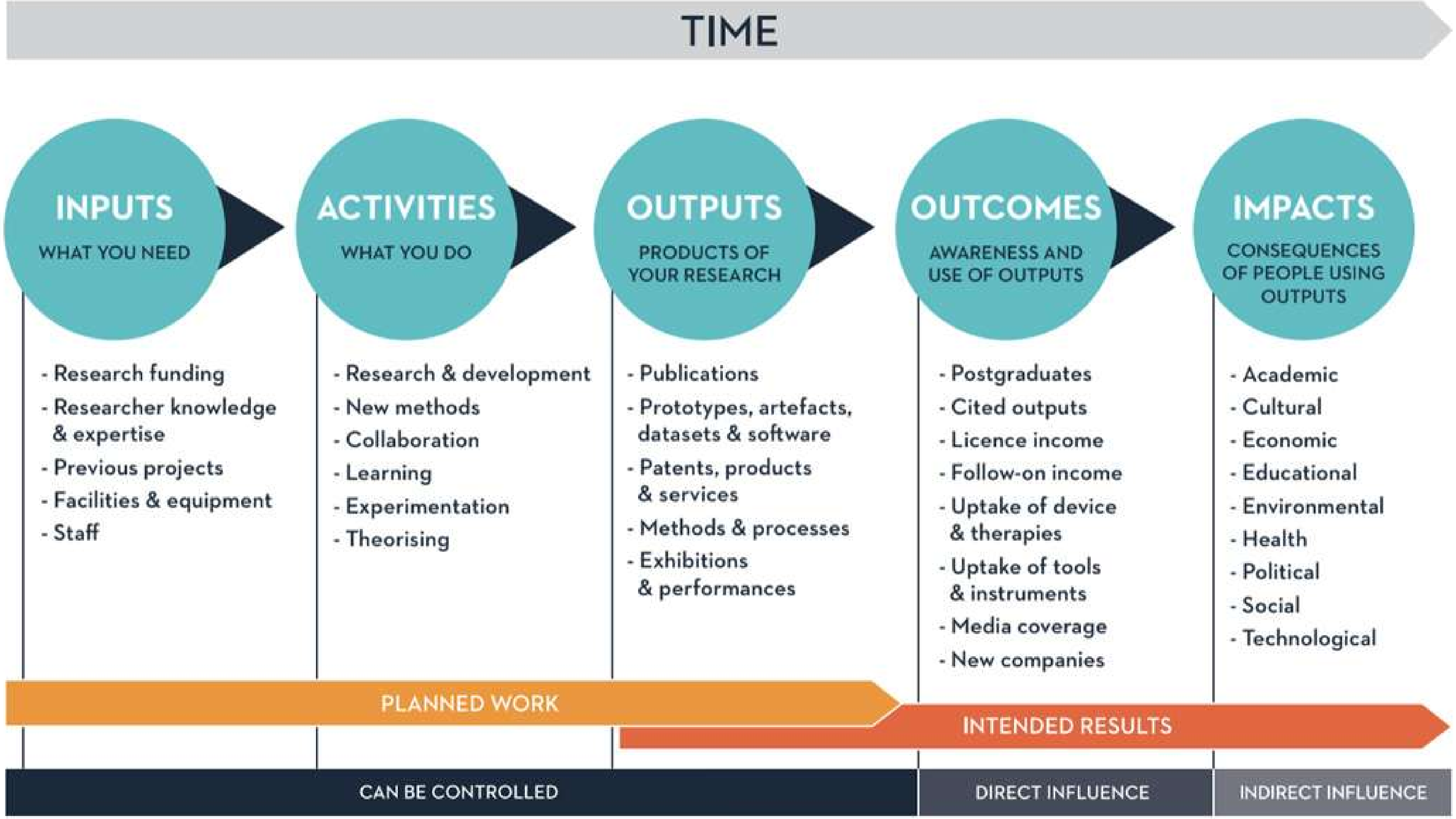
What is research impact?

- The demonstrable contribution that research makes to makes to society, the economy, or culture beyond academia
- Positive effects that research has on individuals, organizations, and/or nations
- Simply put: how research leads to meaningful, demonstrable change in the real world.

Research Impact



"I think you should be more explicit here in step two."



TIME

INPUTS
WHAT YOU NEED

- Research funding
- Researcher knowledge & expertise
- Previous projects
- Facilities & equipment
- Staff

ACTIVITIES
WHAT YOU DO

- Research & development
- New methods
- Collaboration
- Learning
- Experimentation
- Theorising

OUTPUTS
PRODUCTS OF YOUR RESEARCH

- Publications
- Prototypes, artefacts, datasets & software
- Patents, products & services
- Methods & processes
- Exhibitions & performances

OUTCOMES
AWARENESS AND USE OF OUTPUTS

- Postgraduates
- Cited outputs
- Licence income
- Follow-on income
- Uptake of device & therapies
- Uptake of tools & instruments
- Media coverage
- New companies

IMPACTS
CONSEQUENCES OF PEOPLE USING OUTPUTS

- Academic
- Cultural
- Economic
- Educational
- Environmental
- Health
- Political
- Social
- Technological

PLANNED WORK

INTENDED RESULTS

CAN BE CONTROLLED

DIRECT INFLUENCE

INDIRECT INFLUENCE

Output v Outcome v Impact

- Outputs are tangible items created
- Outcomes are short-term changes in behaviour of an output user
- Impacts are the broader, long-term effects on a person on group

- Our research was published in an academic journal **(output)**
- Our publication template is adapted into a medication-safety checklist used in community settings. **(outcome)**
- Emergency and community care teams report fewer repeat clarification calls because medicine instructions are clearer and standardised. **(impact)**

Pop Quiz: Impact or not

- Researchers develop a survey instruments co-designed with carers
- A peer-reviewed article on financial stress among carers
- A hospital team requests a simplified one-page summary to share with families
- Local support groups discuss findings at monthly meetings
- A hospice nursing team integrates a new carer support financial planning step into assessments. Carers report fewer missed allowance deadlines and reduced financial stress

Research Impact

Impact isn’t what *you do*;

it’s what *changes* because of what you did.

Who can accelerate impact

PUBLIC
SECTOR/
GOVERNMENT

INDUSTRY

CHARITIES

LOBBY &
ADVOCACY

COMMERCIA
L

PUBLIC

Workshop

Who are the beneficiaries and influencers?

If the research project is impactful, _who_ should benefit from it?

And who can influence success?

Take 5 minutes to read the scenario and reflect individually, then discuss as a group

Remember

- No “Correct” answers
- Exploring options
- Be creative
- Use your collective knowledge

Tips when considering impact influencers

Who has knowledge that can help you understand translation of findings?

Who has knowledge that can help you understand realities of proposed solutions?

Who will be implementing the outputs/outcomes in practice?

Who will be impacted by the findings?

Who can accelerate or prevent the implementation of the findings?

Part 2: Impact Recipe

Designing action

The new research finding *could* change something in the real world. What needs to happen for that change to *actually occur*?

Create your Impact Recipe

1. What is the core research insight that may translate into impact?
2. Who are the key stakeholders who can make that impact happen?
3. For up to 3 of those stakeholders, what format of communications would get them to notice it?
4. What support or partnerships might make action possible?
5. What real-world change would this create?

Report back

Max of two key learnings from the group

(focus on any “a-ha moments” or areas of specific debate)

In order to achieve impact you need to have relationships, buy-in, and trust with the stakeholders that can help your research be adopted

Thank You for Attending Family Carers Ireland Research Conference
3rd December 2025

#PartnershipInPractice
#familycarers

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